UTILIZATION OF ADULT DAY CARE AND REHABILITATION CENTERS BY PATIENTS SUFFERING FROM ALZHEIMER'S DISEASE AND RELATED DISORDERS IN GEORGIA

A THESIS

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ABSTRACT

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UTILIZATION OF ADULT DAY CARE AND REHABILITATION CENTERS BY PATIENTS SUFFERING FROM ALZHEIMER'S DISEASE AND RELATED DISORDERS IN GEORGIA

Advisor: Dr. Sandra E. Taylor

Thesis dated July, 1990

Adult day care rehabilitation centers represent options for the elderly population that long-term care professionals have long been seeking.

Chapter One represents the statement of the problem, historical overview of adult day care/rehabilitation centers in general and in Georgia, conceptual framework and theoretical grounding and research method.

Chapter Two discusses the problem in contextual review, services, access, quality in adult day care and rehabililitation, the federal government and adult day care programs. Further discussions focus on centers and their relationship of variables from the instrument in the participation of persons suffering from Alzheimer's diseasae and related disorders in Georgia. This chapter seeks also to utilize secondary data on previous studies relating to

adult day care/rehabilitation centers to supplement the study. Primary emphasis was to determine the extent to which those adult day care/rehabilitation centers studied provide for Alzheimer's disease and related disorders patients through their services.

Chapter three will cover presentation of data and discussion in the area of analyzing and examining the centers having Alzheimer's disease and related disorders patients. Presentation of data and interpretation of findings, sampling frame characteristics, key variables and utility and limitation of the study will all be included in this chapter. Included also, will be a comparison of participation of the Alzheimer's disease and related disorders patients between adult day care and rehabilitation centers, a breakdown of adult day care, adult day rehabilitation and combination centers, and the relationship between adult day care and selected variables from the instrument.

Finally, in Chapter Four, a summary of findings, conclusions and study recommendations if need be as to how the adult day care and rehabilitation centers can or should be operated in order to accommodate a greater number of Alzheimer's disease and related disorders cases in Georgia will be addressed.

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DEDICATION

This work is dedicated to the indelible memory of my dear parents, Nchimane Philemon and Sepelong Margaret Mogotsi.

ACKNOWLEDGEMENTS

So many individuals have made an invaluable impact in my personal life and academic growth. I express my genuine gratitude to their contributions.

My special thanks go to Ingrid Saunders-Jones (The Coca-Cola Company, Atlanta), United Nations Educational Training Program for Southern Africans, the Ford Foundation, the Sociology Department (Clark Atlanta University) and the Presbyterian Church (Kentucky), for their financial help. I also acknowledge financial help from the following persons, my cousin, Joe Gadifele Modibane, Alice Kidder, Dr. Dorcas D. Bowles (former Acting President, Clark Atlanta University), Isaac Stan Manning, Ron and Robyn Lewis, Zenzi Miriam Makeba and Ed Charles Brown. I am further indebted to my advisor, Dr. Sandra E. Taylor for her unrelenting guidance and motivation especially during my time of mourning for my mother and sister. Further appreciation goes to my thesis committee members, Drs. Hubert B. Ross and Margaret Counts-Spriggs. Profound gratitude goes to my mother Sepelong Margaret Mogotsi and my sister, Sebolelo Mohajane who both passed away before the completion of this work. Finally, I am beholden to God and my ancestors, whose will and power gave me strength to execute this task.

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CHAPTER I

INTRODUCTION

Statement of the Problem

Georgians, as are all Americans, are living longer today than ever before in history. This rapid aging of the population presents a demographic revolution which is projected to be one of the most influential forces shaping the delivery of human services well into the next century.[2] The importance of this study is evident in the fast growing number of Alzheimer's disease and related disorders patients particularly in Georgia. The National Institute on Aging statistics show that, in 1985, approximately 44,000 Georgians suffered from Alzheimer's disease and related disorders.[3] Furthermore, this same study on growth and projections of the future, states that with the medical advances of the twentieth century, America's population is growing older in numbers and in proportion to the rest of the nation. This growth is expected to continue through the first third of the next century. The increase in the older

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1 Carole L. O'Brien, Adult Day Care: A Practical Guide (California: Wadsworth Inc., 1982), p. 174.

2 State of Georgia's Department of Human Resources Report (December 1987), p. 3.

3 National Institute on Aging, Inc., (Washington, D.C.: February 1985), p. 15.

population grew twice as fast as the rest of the population in the last two decades. The eighty-five plus population is growing even more rapidly and this "very old" of "old-old" group is expected to increase seven times by the middle of the next century. The projections found in Table 1 assume a prevalent rate of 7 percent of the persons over the age of sixty-five and that the number of non-elderly persons having the disease is equivalent to six persons of the number of non-elderly persons having the disease is equivalent to six persons of the number of afflicted older victims sixty-five plus. Based on these assumptions, 44,000 persons are estimated to have suffered from Alzheimer's disease and related disorders in Georgia during 1985. It is reported that this number is expected to grow by almost 34 percent to 57,000 persons by the year 2000.[4] Furthermore, studies reflect that the growing population of Alzheimer's disease and related disorders patients in Georgia poses a problem for the existing adult day care/rehabilitation facilities to meet demands. As a result these centers are unable to adequately provide for them. In addition to these facilities, there are four day care/rehabilitation centers which were specifically developed to meet the needs of

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[4] State of Georgia's Department of Human Resources Report (December 1985), p. 20.

Alzheimer's disease and related disorders in Georgia, but these centers are still unable to meet the needs of the patients adequately, due to the high demand.

Table 1

Alzheimer's Disease and Related Disorders in Georgia

	1985	2000
Population 65 plus	592,000	791,000
Number of Alzheimer's Patients	44,000	58,600

SOURCE: Office of Planning & Budget (Department of Human Resources, Georgia), 1985.

The centers which will be examined are the 35 adult day care and rehabilitation centers affiliated with the Department of Human Resources (DHR), Office of Aging in Atlanta, Georgia. However, there are more adult day care and rehabilitation centers in the state which are not available for this study because they are not affiliated with DHR, Office of Aging.

From the aforementioned information, this study explores the contention that those adult day care and

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[5] Ibid., p. 21.

rehabilitation centers with existing special policy on admissions will be relatively inaccessible to some Alzheimer's disease and related disorders patients. On the other hand, those without existing special policy on admissions will be relatively accessible to Alzheimer's disease and related disorders patients. In this sense, it can be further assumed that the adult day care and rehabilitation centers with a restrictive special policy on admissions will have less patients participating than the adult day care rehabilitation centers with a relatively open policy on admissions.

The study will determine the extent to which bureaucracy plans a role in current social services rendered by these centers to meet the needs of Alzheimer's disease and related disorders patients, and the extent to which the existence of special policy on admission promotes stratification, centralization, and rationalization at facilities where the policy is enforced.

Historical Overview of Adult Day Care/Rehabilitation Centers

A philosophy of adult day care and rehabilitation centers (ADC/R) is that the aged have unique needs which need to be met. In satisfying these needs, advocates of these centers believe that all aged, infirmed and/or

disabled persons should have equal access to programs. The staff employed by these centers also believe that the wellness of an individual is intrinsically linked to the physical, social, and psychological aspects of that persons' life. Therefore, the staff believes in a health promotion and maintenance framework. In addition, the staff is committed to the concept of adult day care/rehabilitation centers and their place within the continuum of care for the physically and/or mentally handicapped aged person. Family and community involvement is also considered essential in the planning of long-term care of each participant. In this way, the staff and board believe in including community and family input at all levels of decision making. Since the goals set with each participant are aimed at obtaining the highest level of independence and wellness for that individual, the belief in individualized care is paramount. Adult day care/rehabilitation centers are considered service programs that serve as a long-term care alternative to the impaired and disabled adults to improve their quality of life. Adults who seek these adult day care/ rehabilitation services mainly are those who want to maintain their independence within the community. A large proportion are handicapped persons who have certain impairments that prohibit them from living independently without any supportive services.

Adult Day Care/Rehabilitation Centers in Georgia

The Georgia Department of Human Resources' Office of Aging works closely with the Council on Aging in advocating for older Georgians. Assisting the Office of Aging are eighteen Area Agencies on Aging (AAA) across the state. Area Agencies on Aging, created through the Older Americans Act, plan, coordinates and advocates for the development of a comprehensive service delivery system to meet the needs of older persons in a specific geographic area. It is estimated that over 2,000 agencies and groups are a part of the comprehensive service delivery system and provide a multiplicity of services to older adults across the state. Within these components exist adult day care and adult rehabilitation services.

Originally, adult day care in Georgia was served by Title XX (a program under the Social Security Act providing services specifically for the elderly). Today, a wide variety of sponsors, ranging from private to public; profit to non-profit making; city/state/federal to governmental; affiliated to non-affiliated and church to synagogue have initiated these programs. There is quite a number of ADC/R centers operating in Georgia; however, this study will focus on the 35 centers registered with DHR/Office of Aging.

Definitions

There is a distinction between adult day care and adult day rehabilitation centers. This can be clearly demonstrated by their definitions and roles respectively. In the case of adult day care there are numerous definitions, as the following depict:

(1) "Day Care" is a program of services provided under health leadership in an ambulatory care setting for adults who do not require 24-hour institutional care and yet, due to physical and/or mental impairment, are not capable of full-time independent living. Participants in the day-care program are referred to the program by their attending physician or by some other appropriate source such as an institutional discharge planning program, a welfare agency, etc. The essential elements of a day-care program are directed toward meeting the health maintenance and restoration needs of participants. However, there are socialization elements in the program which, by overcoming the isolation so often associated with illness in the aged and disabled, are considered vital for the purposes of fostering and maintaining the maximum possible state of health and well-being.

"Impaired adult" means a chronically ill or disabled adult whose illness or disability may not require

twenty-four hour inpatient care by which, in the absence of day-care services, may precipitate admission to or prolong stay in hospital, nursing home or other long-term care facility.[6]

(2) Weissert's (1975) definition states:

Day care is essentially a program designed to serve the elderly, infirmed and disabled who do require 24-hour institutional care but who would benefit by a therapeutic program of social, physical, rehabilitation, dietary services counseling and recreation.

(3) The National Council on Aging (1972) supports the following definition:

Adult Day Care is a program of care during the day for impaired adults in a group setting away from home.[8]

(4) On the other hand, Brakna Trager in September 1976, adapted part of the 1974 federal definition:

Adult Day Care is a program of services provided under health leadership in an ambulatory care setting for adults who do not require 24-hour institutional care and yet, due

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6 Definition of Day Care Services, Public Law (2-603, Section 222 (G). Dept of Health, Education and Welfare, Washington, D.C.: 1974), p. 5.

7 William G. Weissert, Adult Day Care Programs in the United States: Current Research Projects and a Survey of 10 Publi8 Health Reports (January/February, 1975): 92: 49-56.

8 The National Council on Aging, Inc., (Washington, D.C.: 1972), p. 10.

to physical or mental impairment are not capable of full-time independent living.[9]

(5) O'Brien states that adult day care is a blend of psychological and health services that might exist in a variety of balances. What is essential is that the two services (psychosocial and health services) exist together, for the two needs cannot be separated.[10]

(6) Finally, Padula defines adult day care as:

Any program which provides personal care, supervision and an organized program of activities, experiences and therapies during the day in a protective group setting. Day care offers an individualized plan of care designed to maintain impaired persons at, or to restore them to, optimal capability of self-care.[11]

With respect to adult day rehabilitation, the state of Georgia, D.H.R. (1985) states that (i) Adult Day Rehabilitation (ADR) offers ambulatory health care medical

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[9] Brakna Trager, Adult Day Facilities for Treatment, Health Care and Related Services: A Working Paper, (United States Senate Special Committee on Aging, (September, 1976), p. 13.

[10] Carole Luinn O'Brien, Adult Day Care: A Practical Guide (California: Wadsworth Inc., 1982), p. 13.

[11] H. Padula, Developing Day Care for Older People, A Technical Assistance Monograph, Prepared for the Office of Economic Opportunity (Washington, D.C.: National Council on Aging, Inc., September, 1972), p. 59.

supervision and health related supportive services in an adult day rehabilitation center as an alternative to institutionalization. The center may be free standing or housed within an adult day care center of a senior center.[12]

The Atlanta Regional Commission (ARC), Area Plan on Aging, Policy Document (1986-1987) reports the different roles and structural features that distinguish the difference between adult day care and adult rehabilitation centers.[13]

(i) Adult day care provides supervision, social and support services to frail individuals, and does not necessarily include supervision by a registered nurse or require a care plan approved by a physician or rehabilitative services. Allocations under the Social Services Block Grant currently provide adult day care placements in only Cobb and Fulton counties and ARC under Title III funds day care services in Clayton, Cobb and Gwinnett counties.[14]

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[12] State of Georgia's Department of Human Resources Report (December 1985), p. 38.

[13] Atlanta Regional Commission, Area Plan on Aging, Policy Document (1986-1987), p. 124.

[14] Ibid.

(ii) Adult Day Rehabilitation (ADR) funded under the Community Care Program presents an important alternative to nursing home care. ADR centers are open at least five days a week and provide ambulatory health care and health related support services for persons who cannot live independently, but do not require 24-hour care. ADR services are supervised by a registered nurse and are provided under a plan of care approved by a physician. ADR also includes the availability of rehabilitative services such as physical, occupational and speech therapy.[15]

It should be noted that it is possible for adult day care/rehabilitation to be provided within one program. This arrangement is referred to as a "combination" (adult day care/rehabilitation program). In a combination program, persons are enrolled for the level of services needed, either adult care or adult rehabilitation care. Activities and services are provided in the same staff. Combination programs may be operated either as free-standing programs or in a multi-use facility. Padula reports that the adult day care may be a district unit within a senior center; if so, participants may utilize some senior center activities while in the adult day care program or, as they improve, transfer

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15 Ibid.

to a senior center membership in an already familiar setting.[16]

Observing the six given definitions of adult day-care, a common dominating variable of the time participants can spend at the centers is highly emphasized. This factor is also present in the adult day rehabilitation definition. Centers are providing their services to only those adults who do not require 24-hour institutional care. In this way, the Alzheimer's disease and related disorders patients are already placed at a disadvantage because their disease requires an absolute 24-hour care.

Conceptual Framework and Theoretical Grounding

This study is based on the theoretical framework of Max Weber as it pertains to the operation of bureaucracies in social institutions of adult day care and rehabilitation centers. Weber maintains that policy making functions tend to exclude certain members of groups because of strict adherence to formal rules and their proliferation.[17]

A focus of this study is to examine the extent to which bureaucracy impacts participation of patients of Alzheimer's

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[16] Padula, Developing Day Care for Older People, p. 13.

[17] Victor Thompson, A Modern Organization (New York: Alfred A. Knopf, 1961), p. 6.

disease and related disorders in the form of promoting degrees of (i) stratification, (ii) centralization, and (iii) rationalization at the adult day care and rehabilitation centers where policy or other criteria for admissions is in existence in the State of Georgia.

The incorporation of stratification includes a discussion of those who are poor and might not have accessibility to these facilities, perhaps due to reasons involving a lack of knowledge about the facilities. On the other hand, patients from relatively more affluent backgrounds are more likely to have a broader knowledge about available facilities, what they offer, and their basic policies.

Centralization concerns the people who develop and fund these facilities and who have the power of determining physical location. Also categorized under centralization is the making of regulations which can include eligibility, cost, affiliation, staffing, operation and special policy on admissions of prospective participants.

Rationalization is included as a third factor of bureaucracy. There is restrictive policy on admission centers around budget constraints, lack of skilled human resources to manage the facilities, and the dilemma or concern surrounding the uncertainty of full recovery of

Alzheimer's disease and related disorders patients in becoming functional members of the community again, "which is the ultimate goal of the adult day care/rehabilitation centers."

The chosen theory of bureaucracy is propelled by the fact that current interests in problems of organization reflect, to a great extent, the modern person's life as organized for him/her. Education, livelihood, recreation and religion are products of the planned and coordinated activities of great numbers of people, who tend to be peripheral to the contemporary "peasant" existence. Therefore, today's "peasant" can be considered a product of modern organization. His/her fate is vitally affected by an understanding of it, reports Thompson.[18] This study will attempt to explain the impact bureaucracy has on one area of organization in modern society.

The "primitive man" was unspecialized and organized in kinship groups--family groups which served all his needs. As such organization became inadequate for the specialized person, and new forms developed. Today, we live in a highly specialized industrial society. The predominant form of organization is a highly rationalized and impersonal

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[18] Ibid., p. 74.

integration of a large number of specialists cooperating to achieve some announced specific objective. The highly elaborated division of work in such organization is also a highly elaborated hierarchy of authority, thus what Max Weber called "bureaucracy." Weber states that the influence of bureaucracy is felt in nearly all aspects of life, and that many people have a feeling of powerlessness, alienation, and respond with various kinds of behavior.[19] Some are able to manipulate organizations sufficiently well to achieve important aims of their own. Others submit to bureaucratic standards of achievement and find bureaucracy a natural and comfortable habitat. Whatever the form of adjustment, behavior patterns and character types emerge which are bureaucratically conditioned to some important extent. The modern person is becoming a bureaucratic one, or, as Thompson calls an "Organization Man."[20] Modern bureaucracy can therefore be perceived as an adaptation of older organizational forms, altered to meet the needs of specialization. This notion further brings about a growing gap between the right to decide, which is authority, and the power to do, which is specialized ability. In short, many

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19 Ibid.

20 Ibid.

programs fail to meet the needs of a very specific target group which finds itself excluded by the regulations of bureaucracy. This is the case with Alzheimer's disease and related disorders patients who require 24-hour supervision from ADC/R centers in Georgia. It goes without saying that this situation produces tensions which also develops a growing imbalance between ability and authority. To a large extent, this is how promotion of stratification, centralization and rationalization come into play, particularly at centers where as special policy on admission exists. As a result of this impact, Weber conceived of the world as becoming progressively rationalized and demystified, with corresponding change in organizational forms. He states that organizations have grown in size because they must be able fully to employ the new specialists and the specialized equipment associated with them if the organizations are to meet their competition. Weber states that, as more specialists appear and the organization continues to grow in size, it becomes necessary to group employees into units, and the units into larger units. And, some of the larger of these units in government have been called "bureaus", and so the kind of organization resulting from this process has been called "bureaucracy."[21]

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[21] Ibid., p. 75.

It is recorded that the impact of specialization upon modern organization accounts for many of the latter's characteristic features. This is so because the modern organization evolves in response to modern science and technology. This is said to be the spirit of rationalism. No longer are traditional or religious standards to be the guardians of knowledge. Weber further states that the growing dominance of the spirit of rationalism in modern bureaucracy simply reflects the growing influence of scientific and technical specialists upon organizational decisions.[22] Weber highlights that bureaucracy requires "a system of assured careers", otherwise, the individual would not invest the time needed to acquire specialized skills. It also requires that the organization have a definite and reasonably assured division of work into defined jobs or offices.[23] In fact, he implies that the division of work in organizations for the most part, follow the existing specializations in society at large. He states, "to secure stability, continuity and predictability of product, the activities of the organization are reduced to procedures and

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22 Ibid.

23 Ibid.

24 Ibid.

routines."[24] Routinization of organizational activity is implicit in the process of specialization and is a characteristic of bureaucracy. Specialization requires a stable environment and a guarantee of continuity of function. However, the lack or shortage of skilled human resources to man the ADC/R facilities and the predicament of uncertainty that Alzheimer's disease and related disorders patients will fully recover so as to become functional members of their community again is again placed in a dilemma.

In a case of centralization, Max Weber states that when new specialties become available, some old ones must lose functions, even becoming obsolete in the extreme case.[25] In this sense, specialization is viewed in the same way as centralization: many become dependent for these functions on the few new specialists. Within organizations, new specialties can be economically utilized only if sufficient demands can be concentrated to employ fully the new specialists. Activities may therefore be centralized because of the continuing advance of specialization. There are also needs that arise or press for recognition at the point of authority where the right to carry centralization

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[25] Ibid., p. 76.

to this level is located. For one to understand such centralization one must understand the needs in question. Often such needs relate to the desire for personal power and status; sometimes they may be traced to a demand for uniformity or for the recognition of particularistic interests or values. Sometimes they are perhaps related to insecurity generated by the structure of bureaucratic organization. In short, centralization may be the natural result of specialization, or it may be an arbitrary creation by someone with superior power, according to Thompson.[26] Therefore, as mentioned earlier, this statement confirms the assumption that those who fund ADC/R facilities have power of determining physical location and the making of regulations for prospective participants at the centers.

Finally, the concept of stratification comes to play. This is another limitation on task planning arising from definitions associated with hierarchy. The hierarchical relationship is a monocratic one. The superior is to be the only person in the organization who has the right to deal with the subordinate, especially the right to communicate with the subordinate and to tell him what to do. Programs must be allocated to jobs in such a way that the jobs will

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[26] Ibid., p. 81.

fit into this monocratic framework. It has been stated earlier that stratification denies accessibility to the poor and socioeconomically deprived. This fact is clearly demonstrated when Weber states, ". . . the superior has the right to monopolize communication, both official communication between the unit and the outside world and communication between members of the unit." He states further, "that the right to monopolize outgoing communication is often expressed by bitter resistance to the use of specialists, non-hierarchical channels."[27] In other words, it can be concluded that the combined effect of bureaucracy's characteristics is to create social conditions to act in ways that, whether they appear rational or otherwise from his individual standpoint, further the rational pursuit of organizational objectives. Without explicitly stating so, Weber supplies a functional analysis of bureaucracy. In this type of analysis, a social structure is explained by showing how each of its elements contributes to its persistence and effective operations.

Blau (1965) highlights how Robert K. Merton's re-examination of the foregoing discussion of bureaucratic features in the light of the concept of dysfunction reveals

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[27] Ibid., p. 83.

inconsistencies and conflicting tendencies.[28] Merton states that the strict exercise of authority in the interest of discipline induces subordinates, anxious to be highly thought of by their superiors, to conceal defects in operations from superiors, and this obstruction of the flow of information upward in the hierarchy impedes effective management. Merton states further that insistence on conformity also tends to engender rigidities in official conduct and to inhibit the rational exercise of judgement needed for efficient performance of tasks.[29] These illustrations indicate that the same factor that enhances efficiency in one respect often threatens it in another; it may have both functional and dysfunctional consequences.

Research Method

This study utilizes data based on adult day care and rehabilitation centers that are registered with the Office of Aging in the State of Georgia. There are 35 ADC/R facilities presently affiliated with the state, 33 are included in this study. However, there are some other not registered, and as a result posed difficulties to accessibility of information. The ADC/R centers in focus serve quite a number of elderly persons presently residing

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[28] Peter Blau, The Dynamics of Bureaucracy (Chicago: University of Chicago Press, 1956), p. 33-48.

[29] Ibid.

in the State of Georgia; these elderly persons comprise a population age group ranging between under 60 years of age to 85+ years old. The ADC/R centers are essentially programs designed to serve the elderly who do not require 24-hour institutional care, but who can benefit by a therapeutic program of social activity, physical rehabilitation, counseling and recreation.

Data will include numbers of ADC/R centers who utilize special policy on admissions and those who do not have restrictive admission policies obtained through a questionnaire (originally developed by the Department of Human Resources, Office of Aging) to investigate the impact participation of Alzheimer's disease and related disorders patients. In examining the problem, other variables will be studied, including geographical location of ADC/R centers, schedule of operation, number of days of operations and hours, affiliation, funding and reimbursement sources, selected utilization and client information (which includes the degree of Alzheimer's disease or related disorders), age groups, gender, race, Alzheimer's disease and related disorders, special policy on admission, special programs or service to the family, staff ratio, job category (whether full or part-time employees), cost, and physical plan. All of these variables have been found to play significant roles in the participation of the elderly at the ADC/R centers.

The time frame of the study was confined to collecting data within a one-month period via a mail survey. Further information was obtained from gerontological literature and related journals and other statistical reports. Data from various community groups and agencies were also utilized. To interpret data, basic descriptive statistics were used including univariate presentations of data where appropriate.

CHAPTER II

THE PROBLEM IN CONTEXTUAL REVIEW

This section of the literature review examines the extent to which bureaucracy impacts participation of Alzheimer's disease and related disorders patients in the form of promoting degrees of (i) stratification, (ii) centralization, and (iii) rationalization at the ADC/R centers where policy on admissions is in existence or a criterion for admission in the State of Georgia.

The Georgia D.H.R. (1985) states that Alzheimer's disease is estimated to affect 30 to 50 percent or more of all nursing home residents. In 1984, Georgia spent $248.8 million or 40 percent of its total Medicaid budget on nursing home care. Expenditures for individuals with Alzheimer's disease were responsible for $74.6 to $124.4 million of those nursing home dollars. The cost of the disease to the patient, of course, is tremendous. The disease can have its onset in the wage earning years, especially bringing financial duress to the household where the primary or sole breadwinner is afflicted. Even in cases where the non or secondary wage earner is affected, financial loss is great, often because the breadwinner is forced to give up his/her job to take on the increasingly consuming responsibility of caring for the patient.

The Area Plan on Aging, Policy Document (1986-87)[30] states that due to inadequate financial resources, many do not qualify for public assistance, yet their incomes are insufficient to pay private fees. Therefore, financial constraints already place the above category of patients at a disadvantage of enjoying the benefits of ADC/R centers. With continued improvements in social security and pension plans,it is expected that the post-retirement income of the older population will be more adequate. However, it should be noted that there are certain subgroups within the older population that still have high poverty rates--females, minorities, those who live alone, and the oldest of the old. These subgroups, women and minorities in particular, are said to have generally worked less or held lower paying occupations on the average and therefore tend to have fewer financial assets to rely on after retirement.

Other barriers experienced by older persons in obtaining services, according to the Area Plan on Aging, include the inaccessibility of services whereby providers fail to publicize their services and telephone numbers, no evening or weekend services, and the inability of agencies to respond because they have too many referrals. Without

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30 The Atlanta Regional Commission, Area Plan on Aging, Policy Document (Atlanta, Georgia: 1986-87), p. 92.

accessibility to this kind of information, poor prospective participants are likely precluded from being participants of ADC/R centers. Even those who are literate or those who are from relatively more affluent backgrounds will be hindered from being part of this program because of its lack of publicity.[31]

Palmer 1985, reports that as with all types of care, access, quality, and cost are central to any consideration of ADC/R centers. A fragment funding situation, coupled with a lack of program initiative in the public sector, probably has reduced access to existing ADC/R facilities and programs. It is thought that an extensive research, however, is needed to determine the actual and potential need and possible utilization of ADC/R services, to identify the effects of the reimbursement systems under various public funding programs,and to assess the consequences of pen entitlement of ADC/R centers for all disabled in the community without a means of test.[32]

Regarding centralization, the Standards of Georgia, D.H.R., Standards for ADC/R propose that the centers shall

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[31] Ibid., p. 92.

[32] Hans C. Palmer, Long-Term Care Perspectives from Research (New York: Aspen Publication, 1985), p. 401.

centers shall have a governing body which is identified and defined as having full responsibility for the overall conduct of the centers.[33]

1. The governing body shall assure that all laws, regulations, rules and ordinances of state and local governments which apply to its operation are met.

2. The governing body shall establish written policies and procedures that assure the purposes of the centers are met including providing a safe and protective environment for the participants.

(a) Policies shall further state the number of participants served, operational hours, services offered, rates and payments and procedures for assisting with medication and emergencies.

(b) Policies shall also state that the centers shall not accept participants whose needs cannot be met by the centers.

(c) Policies shall state that day care services which are provided in facilities offering other services or programs are not pre-emptied of space or staff needed for proper operation of the adult day care program.

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[33] Standards of Georgia, Department of Human Resources Standards for Adult Day Care/Rehabilitation Centers(Atlanta, Georgia: 1984), p. 2.

(d) Policies shall state admission and discharge or termination criteria and procedures. Procedures for open communication between the staff of the center and the participants and their families shall be established. Policies shall provide for access by family member or responsible respresentative to all parts of the facility used by participants.

(e) Policies and procedures of the center and a copy of the state standards shall be available to participants, their families and other interested persons.

3. The governing body shall have in writing procedures and agreements describing working relationships with a hospital, rehabilitative center and/or any other health agency from which participants may obtain any emergency health care services.

4. The governing body shall establish and maintain sound fiscal management inclusive of an annual budget, monthly accounts of income and expenditure and an annual audit.

5. The governing body shall provide for adequate liability insurance coverage for the staff, facility, participants, volunteers and vehicles. Such liability

insurance shall include personal accident and injury coverage.[34]

It should be taken into consideration that whenever ADC/R programs are developed, an assumption that everything likely to benefit a specific target group is done, irrespective of the cost. However, this assumption cannot be continued, for resources are not limitless and available funds must be put to the most valuable use.

It was reported that as costs escalate in long-term care delivery care delivery, providers of adult day care services are concerned that these programs be both effective in achieving desired outcomes (cost-benefit analysis) and efficient in resources utilization (cost- effectiveness analysis). Not only do planners need to look at result outcomes, but they must also relate these outcomes to cost. In addition, they need to relate program costs to other alternative programs for the purpose of identifying the program's cost effectiveness. Cost benefits are the relationship or ratio of the economic costs (direct and indirect) of a given type of illness to the benefits derived from a given program.

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[34] Ibid., p. 6.

A study by Panella cites two major problems by families of Alzheimer's disease patients: (i) the cost of the day care program, and (ii) the problem of patient transportation.[35] In addition, several families believe that the program could provide greater service if the center's hours were longer. Transportation plays a significant role in influencing the elderly's participation at these facilities; so does their limited financial resources.

Finally, the degree of rationalization is based on skilled human resources to manage the facilities, particularly where patients of Alzheimer's disease and related disorders are involved. Since Alzheimer's disease patients require 24-hour attention, it is thought that the training of personnel and the establishment of appropriate personnel standards and practices can cripple the facilities' budgets. So, in this way, such a policy excludes Alzheimer's patients. It must also be noted that, historically, few agencies have offered services to meet the special needs of Alzheimer's disease patients and their

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[35] J. Panella, Jr., and F. McDowell, Day Care for Dementia: A Manual of Instruction for Developing a Program, "The Burke Rehabilitation Center Auxiliary", Burke Rehabilitation Center (New York: White Plains, 1983), p. 886.

caregivers. Perhaps, of the factors for this reason is that (i) agency workers were untrained in caring for Alzheimer's patients; (ii) the cost of care is too expensive; and (iii) programs are not appropriate for persons with memory impairments and declining intellectual capacities. Also is the dilemma or concern surrounding the uncertainty that these patients will fully recover and become functional members of the community again. This factor is stated in the target population regulations by the National Institute on ADC report "Only applicants who can be expected to improve within a stated period of time will be accepted."[36]

It is the study's assumption that those ADC/R's with existing special policy on admissions will be relative inaccessible to some Alzheimer's disease patients and those ADC/R without special policy on admissions will be relatively accessible. This assumption is made on the basis of an institution's implementation of regulations and ensuing degrees of heightened bureaucracy.

According to Vogel, in the United States, major initiatives for the development of adult day care and rehabilitation programs came from the community, not from Federal or State agencies or funding service unlike in other

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[36] The National Institute of Adult Day Care Report, p. 31.

European countries. In 1980, there were about 617 adult day care and rehabilitation programs in 46 states. Their average daily census (1980) was about 13,500. The number of sites has grown rapidly, from 200 in 1977 to 300 in 1978, and to 600 in 1979.[37]

Sources of support for adult day care and rehabilitation programs vary greatly. Overall studies state that few public financial support programs directly reimburse for total adult day care and rehabilitation programs. Rather, there is a provision for specific services, such as nursing, physical and occupational therapy, medical social work, etc. For example, in two-thirds of these states, Medicaid, pays for certain specified services, varying among jurisdictions. It covers specified services, regardless of site provision, as long as the services are prescribed by a physician and/or meet other regulations. In addition, under Title III of the Older Americans Act, administered by the Administration on Aging (AOA), some states support adult day care and rehabilitation type services.

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[37] Ronald J. Vogel and Hans C. Palmer, Long-Term Care Perspectives from Research and Demonstrations (New York: Aspen Publication, 1985), p. 416.

In addition to the major Federal and State programs cited earlier, other support for adult day care and rehabilitation programs comes from voluntary agencies (for example, United Way), philanthropic groups, local governments, and some federally funded demonstrations conducted under Medicare waivers. Some health insurance carriers cover adult day care and rehabilitation, and out-of-pocket fees also are assessed, often on an income-linked, sliding scale. Because of the integration of adult day care-related services with other types of health care, it has been difficult to determine the amounts spent by these various sources on respective programs. Knowledgeable observers suggest, however, that possibly 50 percent of the costs of some adult day care and rehabilitation programs are being paid out-of-pocket and such fragmentation in funding support can contribute to fragmentation of programs, that may lead to confusion among users and providers and lessening the beneficial results which adult day care and rehabilitation might have.

Types of Adult Day Care Services

Adult day care services are sometimes grouped into various "models", such as restorative, maintenance, and social. The restorative model presumably has an intensive health care focus, emphasizing constant monitoring,

one-on-one therapy, and psycho-social (as well as medical) services. Maintenance programs are of longer duration, but they also emphasize individual care plans with periodic reassessments with much less intense monitoring and often with group therapies. Social programs, though often directed by a registered nurse, are more activity-oriented than health-oriented, offering services to lonely, old clients in a protected environment and, at times, arranging for therapies outside the adult day care site.[38] Some social adult day care programs strive to keep clients in the community as long as possible by keeping them in contact with their environment.[39] As mentioned earlier, some facilities offer joint levels of care, but most stress one of the listed types of programs. Weissert also has provided a useful classification for analyzing adult day care and rehabilitation systems. Model I focuses heavily on rehabilitation and emphasizes medical provision. Model II has a more social orientation, often approaching the British Day Center in its wide ranging provision of social and

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38 Ibid., p. 417.

39 Brahna Trager, Adult Day Health Care--A Conference Report, Arlington, Virginia, September 1977d, Tucson, Arizona, September 1978 under Grant No. 1 R13HS 10580-01, National Center for Health Services Research, OASH, May 1979.

recreational services and in its focus on enhancing the social life of the patients whose needs are for maintenance; Model I focuses more on therapeutic treatment of diseases. Of course, these distinctions are a bit arbitrary as are the services supposedly found in each.[40] Nonetheless, this typology--much like the previously discussed three level models--provides some useful axes for comparison among programs. Also, it may facilitate comparison between adult day care and rehabilitation and other care modes, for future studies.

In general, as with all other aspects of long-term care, functional disability, coupled with weak social support systems, make people logical candidates for adult day care and rehabilitation programs. In identifying possible clients, patient medical condition, the severity of that condition, and the lack of a suitable support structure all combine to form the profile of need. In light of these determinants of need, enthusiasm for emphasizing so called preventive efforts of adult day care and rehabilitation without an educated awareness of the need to set goals, consider the feasibility of restorative programs, and note

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40 William G. Weissert, "Two Models of Geriatric Day Care: Findings from a Comparative Study," The Gerontologist, October 1976, pp.420-427.

the other subtle effects that produce surprising outcomes can lead to major disappointments. Mental health issues are central to the establishment, analysis and success of any adult day care and rehabilitation program, as they are for any type of long-term care,, since mental health problems (especially among the elderly) often accompany medical problems and since clients with socio-medical difficulties can disrupt any adult day care and rehabilitation organization and program. During episodes of mental illness, adult day care and rehabilitation may not be of any use to them.[41]

The services required in successful adult day care and rehabilitation programs are very complex. In most cases, health services or, at least, supervision are necessary. Nursing care is often a key element. Vogel and Palmer recommend that information and referral services are essential in coping with complicated socio-medical problems, as are the efforts of client assessors, care planners, counselors, and others who can assist with integrating patients into (or back into) the community. These activities might, to varying degrees, also be found in other care modalities, but the community interaction of adult day

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41 Ibid.

care and rehabilitation programs and their express purpose of keeping clients in the community, while offering socio-economic assistance, renders some of the services all the more critical.[42]

To some extent, providing transportation in adult day care and rehabilitation has generated much controversy. According to Vogel and Palmer, transportation services are crucial for outreach to the community to bring in many clients who otherwise could not come in.[43] Others argue that the adult day care and rehabilitation centers should not provide too much transport, since family involvement and contributions are crucial to the success of any adult day care and rehabilitation program. Both sides, however, agree that transportation should emphasize the use of multi-purpose equipment. A key problem with transport, of course, is its cost, which can often reach 50 percent of program expenditures.[44]

In providing service, proper space is central to success. Not only must space be adequate, but also access to needed services and supports must be guaranteed. For

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42 Ibid.

43 Ibid.

44 Ibid., p. 418.

example, the rehabilitation facilities suggest a tied relationship to a hospital or other high-level care facility; in others, the adult day care site should probably be free standing. Within the adult day care and rehabilitation site, the need to incorporate a number of services puts a premium on the close interactions of specialists in a number of disciplines, who must be able to assume other roles and shift emphasis in mounting a team effort, another crucial aspect of successful adult day care and rehabilitation services.[45]

Access and Quality in Adult Day Care and Rehabilitation

As with all types of care, access, quality, and cost are central to any consideration of adult day care and rehabilitation. Studies indicate that a fragemented funding situation, coupled with a lack of program initiative in the public sector, probably has reduced access to existing adult day care and rehabilitation services and precluded the development of new adult care and rehabilitation facilities and programs. Studies also suggest that extensive research, however, is needed to determine the actual and possible utilization of adult day care and rehabilitation, to identify the effects of the reimbursement systems under

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[45] Ibid.

various public funding programs, and to assess the consequences of open entitlement of adult day care.

Among the more important access-related questions are those associated with the organization of adult day and rehabilitation facilities and their relationships to each other. Regarding quality in adult day care and rehabilitation, it seems clear however, that input quality standards related to staff number and type, the definition of program and staff goals, the development of team capabilities and a good data system are important. Good output quality requires identification of changing functional status, measures of re-integration into the community, and means of enhancing the self-perception of individuals.

Eligibility for the adult day care and rehabilitation program is determined by one or more of the following characteristics: the client's need for medical and/or nursing services; the possible usefulness of rehabilitative and/or emotional support services in facilitating the client's return as a functioning member to the community; a high risk of nursing home placement for the client; the possibility that the client, presently in a nursing home, could, with adult day care and rehabilitation, return to the community.

A number of individual state adult day care and rehabilitation programs have been analyzed by administrators in the states concerned. According to Vogel and Palmer, Massachusetts has one of the most extensive programs in adult day care and rehabilitation. Beginning with six sites in 1975 (using Section 222 authorizations), the state Medicaid authorities increased the number the number of sites to 45, serving 807 clients as of August 1979.[46] The experiments are said to have been undertaken because of the increasing public attention to a wider variety of service options. Like many other programs, the objectives of the Massachusetts ADC program are to provide alternatives to institutionalization or to delay it; to provide respite for families who may have to manage heavy nursing care responsibilities at home or who, in desperation, may have to turn to institutionalization; and to provide cost-effective care options to policymakers and to vulnerable populations. Outreach, both in case-findings and educating the public about adult day care and rehabilitation is deemed a crucial part of the Massachusetts effort.

Initially, the Massachusetts Adult Day Health Program is said to have been organized on a three-part (restorative

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[46] Ibid., p. 422.

maintenance, and social) model, but the state authorities decided that it be based on six desired outcomes (to restore health, provide therapeutic recreation and services, provide social services and counseling, provide personal care, assist with adequate nutrition and provide necessary transport).

The client's need for medical and/or nursing services, and rehabilitative and/or emotional support services that may enable the client to return to the community are criteria for eligibility. The adult day care and rehabilitation center sites are open eight hours a day, five days a week. It is mandatory for participants to spend six hours a day at the center (exclusive of transport. A minimum of a two-person staff is required; otherwise there must be one staff professional for no more than six patients. It is required that a registered nurse must be present for four hours a day, and all sites must be barrier free for wheel chair-bound and other handicapped patients.

Clients for the Massachusetts program are admitted after a three week regimen of visits, interviews, and assessments by a multi-disciplinary team. Data from the activities in fiscal year 1978 showed 336 new admissions, 52 percent of whom came from health related facilities, 22 percent from community organizations (home care providers,

social workers, etc.) and 14 percent from self or family referral.[47] The 1978 fiscal year is claimed to have increased success, as well as visibility for the program.

Statistics also reveal that large proportions of the clients were over age 50 (79 percent; 46 percent over age 75) and female(65 percent).[48] There were however, some inconveniences experienced at the Massachusetts program. The participants who were mentally ill were reported to have been disruptive to the other clients. Others had transportation difficulties while some left because they could not afford the fees and/or their Medicaid eligibility had run out under state regulations.

The Massachusetts adult day care and rehabilitation program seems to meet a need among Medicaid eligible clients, since 69 percent of the participants were in that category. The daily capacity of the system was 400 places, and on the average, clients attended 2.3 times per week. If the centers operated 100 percent of capacity, program costs per client came to $13.16 per day; at 80% percent, they amounted to $16.46. Staff allocations absorbed 74 percent of total costs; overhead and other program costs

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47 Ibid., p. 421.

48 Ibid., p. 422.

(independent of staff) accounted for the rest. Transport costs were estimated at $4 to $5 per round trip per person traveling in adult day care and rehabilitation vehicles or other community vehicles. Based on these figures and assessments of clients' satisfaction (and provider perceptions), the Massachusetts authorities claimed that their adult day care and rehabilitation program was cost-effective.[49] Finally, the Massachusetts reports are considered to be instructive for their insights about client characteristics, the role of transport, the technical possibility of maintaining highly disabled people in an adult day care and rehabilitation supported environment, and the need for a multi-faceted approach to adult day and rehabilitation.

Some of California reports are particularly interesting because they focus on changes in the conditions of the adult day care and rehabilitation clients and because they are concerned with comparative costs.

On the cost side, the California officials claimed that the chronically sick not in adult day care and rehabilitation programs were significantly more expensive (in terms of state revenue allocations) than were adult day

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[49] Ibid., p. 424.

care and rehabilitation clients.[50] Overall, the total cost of services provided by MediCal (California's Medicaid program), Social Security Insurance and home care (used by 14 percent of the San Diego and 33 percent of the Sacramento adult day care and rehabilitation clients) was $396.51 per month, well below that of nursing home provision.[51] As with the Massachusetts reports, those from California are rich in institutional detail, but they provide modest information on assessing costs and effectiveness (for example, no data were presented on the dimensions of comparability).

The work of Kierhart and Weissert offers some insights into both the substantive issues and the problems inherent in assessing adult day care and rehabilitation or any other alternative care mode.[52]

Kierhart's survey in the early 1970s of adult day care and rehabilitation programs found only fifteen which met the conventional and federal definition of adult day care and

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50 Ibid.

51 Ibid., p. 425.

52 The Reports and Censuses of Edith Robbins of HCFA provide us with virtually the only overall source of information on the characteristics of adult day care and rehabilitation programs and clients.

rehabilitation.[53] Over half of these were found to be federally funded demonstrations. It was reported also that the average patient load was 40; the modal attendance was three to four days per week. Furthermore, over half of the patients lived alone, 25 percent with a spouse, and 16 percent with a child. Reports state that in most cases, admittance to the program was contingent on having a "stable home environment" (thus possibly indicating the key role of the "relevant other"), displaying no harmful behavior, not being bed ridden, being able to pay for a portion of the care provided and having a physician available in the community.[54]

Both the Kierhart study and the Massachusetts data discussed earlier indicate that large numbers of adult care and rehabilitation clients live alone.

Weissert's studies cover first, some older, established programs and, second a series of Section 222 experiments (under P.L. 92-603) mandated by Congress in 1972. These experiments and research first covered ten sites and later six projects under 22 Medicare waivers. In both sets of

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[53] Kiehart's study in Doherty, Segal and Hicks, 1978.

[54] Vogel and Palmer, Long-Term Care Perspectives from Research, p. 425.

experiments, the following questions were central to the analysis:

- Would the provided services reduce institutionalization?
- What would their impact be on the costs and use of their Medicare-supported services?
- Would the services be effective in maintaining or improving physical, psychosocial, and/or activities of daily living (adult day care and rehabilitation) functioning?
- Would the service postpone death?

Weissert claims that adult day care and rehabilitation care cost could be lower than nursing home costs by as much as 37 to 60 percent at least to the third-party payers.[55] On the Section 222 adult day care and rehabilitation experiment which its intent was to see whether the provision of adult day care and rehabilitation services emphasizing rehabilitation and medical care made any difference in terms of institutionalization and certain health and psycho-social outcomes (including death) and to explore differences in costs. Weissert found that the adult day care and rehabilitation group experienced a lower rate of attendance

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[55] Ibid., p. 426.

which might indicate that most of the people in the demonstrations were not destined for institutionalization any way.

Weissert's analysis offers one of the first rigorous attempts to cast out the adult day care and rehabilitation and nursing home comparison in terms of the magnitudes which must must be considered. His main policy and analytical point in that adult day care and rehabilitation and other alternative programs may be add-ons rather than substitutes for existing regimes of care, especially the nursing home. This conclusion is even more emphasized in Weissert's later work. Grimaldi put the point well when he says that, if this is so, the key question may be whether society is interested in enhancing the lives of the elderly, not whether one form of care is more cost-effective than another. The applicability of this observation to the whole range of alternatives is obvious.[56] Another somewhat equivocal finding in the Weissert's analysis was that adult day care and rehabilitation may reduce mortality among users, but just exactly how is not clearly explained. (It should be noted that Weissert's mortality findings may

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[56] Paul L. Grimaldi, "The Cost of Adult Day Care and Nursing Home Care: A Dissenting View", and Weissert's "Rebuttal", Inquiry, Summer, 1979, pp. 16-26.

derive from methodological problems, since 25 percent of the original experimental group refused the adult day care and rehabilitation services and was excluded from the analysis). Because non-users were reported to be older, more likely to be in institutions, and had a higher death rate than users, the mortality rates among the original experimental group may have been understated. Adult day care and rehabilitation users are also reported to have seemed more contented than non-users and seemed to have higher levels of activity and mental functioning. These outcomes may be the most important from the perspective of enhanced quality of life, reinforcing the claims of some adult day care and rehabilitation supporters.

The Federal Government and Adult Day Care

Research by Weissert (1977) which focuses on adult day care programs in the United States, discusses research projects in a survey of ten centers."[57] It is reported that this study came into being due to slow growth of adult day care in the United States, which was assumed to be attributed to unanticipated (and now unwanted) consequences of private and public health insurance policies,

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[57] William G. Weisert, "Public Health Reports", Health of the Elderly 92:1 (January-February 1977), p. 49.

particularly Medicaid and Medicare. Medicaid and Medicare in particular are reported to have long favored federal payment only for institutional care as a way of discouraging frivolous entry into the health care system. It reported further that for years, many of the most commonly needed services for aged adults (diagnosis, supervision, assistance with activities of daily living) could be reimbursed only if they were obtained in an institutional setting such as a hospital or nursing home.

But as health car costs, especially institutional costs, began to threaten the public purse, alternatives were sought. Late in 1972, Congress formally directed the Secretary of the Department of Health, Education, and Welfare to undertake a study of alternatives to institutional care. The Social Security Amendments of 1972 (Public Law 92-603, Section 222) specified that adult day care would be one of the alternatives considered. The law states, in part, that the Secretary shall:

> "... establish an experimental program to provide day-care services, which shall consist of such personal care, supervision, services as the Secretary shall by regulation prescribe, for individuals eligible to enroll in the supplemental medical insurance program established under Part B of Title XVIII and Title XIX of the Social Security Act, in day-care

> centers which meet such standards as the Secretary shall by regulation establish.[58]

There were also several efforts mounted by the Department to carry out the congressional mandate. Among them was funding in 1974 by the National Center for Health Services Research (NCHSR) of a study of ten existing adult day care programs. A first attempt was at describing the new care mode.

The design of the study required a three-step process for site selection: (i) the universe was defined by adopting minimum inclusionary and exclusionary criteria, (ii) characteristics of agencies essential for inclusion in the sample were identified, and (iii) subsequently ten centers were selected from the eighteen which constituted the known universe of those which met the minimum criteria. Some of the criteria for a center to be included were the following:

(a) A center had to provide the services of the equivalent of one full-time health care professional per week. (Several health care professionals each providing part-time services, could fulfill this requirement, but their total work hours had to equal 35 or more per week.)

(b) Each center had to offer a program of activities, either social or recreational, or both (thus excluding simple health care clinics).

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[58] Ibid.

(c) Included also was type of affiliation (health care facility or other type of agency), location (rural or urban), size of client population (fewer or more than 30 participants attending per day), ethnicity of population served (ethnically homogeneous or heterogeneous and black or the non-white minority), and single and multi-side operations.

Centers were excluded from the sampling universe if they provided overnight care to the day care participants. Day care programs in nursing homes could have been included, but a program labeled as day care which indistinguishable from a short institutional stay was included. Also excluded were programs offering exclusively psychiatric care or servicing a population comprised predominantly of patients with psychiatric diagnoses. However, the study does recognize a psychiatric day care as a well-established service, but it is stated that the survey was focussed on agencies which were engaged predominantly in the innovative effort of providing day care to adults who suffered primarily from physical disabilities, and psychiatric are might or might not be one of their services.[59]

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[59] Ibid., p. 50.

A summary of the findings include the history, goals, admission criteria, intake procedures, staffing, services, population characteristics, referral sources, type of affiliation and daily costs of operations for each center. The following observations were cited:

(a) Facilities, affiliation and size: Adult day care programs varied widely in physical facilities, size and affiliation. One program, On Lok Senior Health Services Center in San Francisco, California is unaffiliated with its administration offices located in a county health department building, but the center operates in another converted building, consisting of basic furniture for recreation, eating and relaxation. The Burke Day Hospital is in stark contrast to On Lok. It operates in a separate wing of the Burke Rehabilitation Center, a voluntary, non-profit rehabilitation hospital in White Plains, New York. Burke is reported to have its own x-ray and laboratory facilities and well-equipped therapy rooms. St. Camillus Health Care by the Day Program in Syracuse, New York, contrasts with both Burke and On Lok in being totally integrated into services and facilities of an extended care facility, with no special quarters for the adult day care program and no segregation between the facility's inpatients and those in adult day care.

Patient loads ranged from 11 participants attending on an average day at the Athens, Georgia's Brightwood Day Care Center and St. Otto's Day Care Program in Little Falls, Minnesota to 115 participants per day at the six sites. The average attendance for the ten programs was 37.5 participants per day.

(b) Funding: Four programs were funded as demonstration projects under Title IV, Part B, of the Older Americans Act. For On Lok, Mosholu-Montefiore Geriatric Day Care Program, and Burke, it is reported that these grant funds constituted the principal source of program support. The Levindale Adult Day Treatment Program in Baltimore is reported to have used these funds exclusively to support the program's research component; its operating funds came mostly from Medicaid reimbursement payment.

Funds allocated under Title VI of the Social Security Act comprised the principal revenue for the Athens center and the Lexington, Kentucky Center for Creative Living, and revenue sharing funds supported the San Diego, California Senior Adult Day Care Program. Medicaid reimbursement comprised the major revenue source for only three programs; all were affiliated with a long-term care facility. These three and most others received some in-kind or direct support from affiliated facilities.

(c) Demographic Characteristics of Participants: Participants in adult day care were as varied demographically as the programs themselves. Several programs were found to have served a catchment area dominated by a particular racial or ethnic group; On Lok is classified as a typical example. (None of the programs are believed not to have excluded persons because of race, creed or national origin.) On Lok indicated three-quarters of its participants were Chinese, and the remainder Filipinos or Italians. Some centers had 95 percent immigrants and at several, most participants were Jewish. The average age of participants also varied by program. It was found that for the entire study, the average was 71 years, however Burke had many participants under 60.

(d) Participants' Impairments: Participants in the survey sample had between two and five diagnosed medical problems. By agency, they varied substantially in the level of dependency according to activities of daily living (ADL) index. More than half of the persons attending Burke Day Hospital were said to be partially or totally paralyzed; just under half of St. Camillus were similarly afflicted. Paralyzed participants made up between a tenth and a third of those attending other programs. Mental illness was the primary diagnosis for nearly three-fourths of St.Otto's

participants, and it afflicted between a fourth and a third or more of the participants in five of the programs surveyed.

(e) Admissions criteria: Burke did not accept a participant who did not have a caretaker at home in the evenings or if the person needed night-time supervision. It is not clearly specified, in what way did Burke and a few other programs exclude participants who did not appear likely to benefit from the health care services offered. Burke and other programs did not accept participants who did qualify for Medicaid but were unable to pay the program's daily charges. Levindale admitted only those who qualified for institutionalization and reimbursement under the Maryland State Medicaid program. Several programs required that participants have their own physicians, since most programs had no staff physicians. None accepted participants who were totally disoriented or dangerous to themselves or to others. All but one program did not accept residents of mental institutions; St. Otto's was the exception. St. Otto's began as a geriatric program, but it evolved into a center for those with psychiatric problems after the state began to release massive numbers of residents of mental institutions. Despite this list of exclusions and restrictions, rigorous criteria regarding

health status or medical diagnoses are reported to be the exception rather than the rule for admission to adult day care. Most programs required that "a medical need must be established", but they tended not to define this term operationally. Only Burke Hospital and the St. Camillus program were exceptions.

(f) Staffing: Several programs depended on affiliated institutions to provide therapy services; others had in-house staff. Tucson had a large total staff of professional, allied, and associated health care personnel, but it also had the largest patient population, giving it paradoxically, one of the smaller staffs in proportion to its population. Burke had the highest ratio of staff to participants. Overall, the range was from nearly one staff member for every participant at Burke and just over one staff member per five participants at St. Otto's. Burke had the largest professional health care staff, the equivalent of 10.5 full-time professionals but its professional staff was extraordinary when compared to the other programs. The range was from 4 participants per professional at Burke to 33 at the Athens center.

Burke's large staff represented a range of health care specialties; it included a Primex nurse (who offered some primary medical care), registered and licensed practical

nurses, speech, physical and occupational therapists. The professional staff of Tucson, St. Camillus, San Diego and On Lok also included several health care specialties, but each lacked a Primex nurse and one other specially compared to the Burke staff. Montefiore, Tucson and On Lok were served part time by a physician. The remaining seven required participants to have their own physicians.

(g) Health care services: Staff interviews were conducted to determine what proportion of staff time was spent in various activities. Of particular interest was the proportion devoted to health care services. (This term was defined in the study as medical and nursing services; physical, occupational and speech therapy; psychiatric and psychological counseling; and the limited time devoted to conference and record-keeping that was directly involved with care giving.) It is reported that the ten programs defined their priorities differently. Half of the time of staff members at Burke (both professional and non-professional) was spent in health care activities, more than 1.5 hours per participant per day. At St. Camillus with a smaller staff and a slightly smaller proportion of staff time devoted to health care services, participants received 85 minutes of such services per day. The San Diego program ranked third in total minutes per day (70.5 minutes)

devoted to such care. The remaining seven programs, staff devoted between a fourth and a third of their time to giving health care to participants. This proportion tended to be about half an hour per participant per day. However, of the seven programs, Levindale gave just 15 minutes per day, but this amount reflected the small size of its staff to some extent. As a proportion of all activities, 15 minutes represented a third of the staff time, or about average for the majority of the adult day care programs studied.

At one program, Athens, participants were given 20 minutes daily which approximated 10 percent of its staff time to the administration of health care services. The other 90 percent of the day, staff was reported to be engaged in participants' social recreational, nutritional, and other supporting activities, but not in receiving health care.

(h) Services: The study found that few aspects of adult day care better evidenced its evolving nature than the heterogeneity of service packages among the 10 agencies. Every program offered a cover of basic services without which it probably could not function. Basic services intertwined among the programs, while added or marginal services were implemented at some centers, for example, only three made a psychiatrist's services available, six programs

gave dietary counseling to participants and their families, half the programs provided physical and occupational therapy and two offered speech therapy. Transportation was provided by only two of the ten programs. It is reported that some carried patients to a range of community, social and recreational agencies; others took them only to other facilities providing health services. Some agencies provided or contracted for transportation only between the participants' homes and the adult day care program.

(i) Costs: The wide variations among adult day care programs in physical facilities, staff size, and variety of health care professionals and services my result in differences in their ability to serve different populations; these facts were brought forth in this study. Under this category, Burke's per diem costs were reported to be much higher than all the other programs. In fact, its costs are said to have been nearly twice as high as for the next most costly program (Montefiore, $33.67), and nearly three times the average of the other nine programs ($21.04). But with that exception, costs fell within a fairly narrow range. The study concluded that adult day care was more expensive than many people may have expected. On a daily basis, the average cost of these ten programs substantially exceeded the average daily cost of nursing homes which, according to

the National Center for Health Statistics, was $15.63 in 1973-74.

The results of Weissert's study are reported to have indicated that the concept of adult day care means different things to different people. Reports further state that some practitioners regard it essentially as rehabilitative therapy for post hospital patients. Others see it principally as supplying social and nurtritional services and some health care, but only for patients who have limited dependency in activities of daily living. Similarly, some program designers target their services expressly to participants of one type, while others accept a variety of client types.[60]

Weissert further highlights that a pattern of two types of programs could be distinguished from the study. The first type is narrowly defined in its service objectives and is targeted to a homogeneous group of participants who meet very specific "admission criteria" which "stress health status." The second type includes a variety of sub-types. These programs are said to be more oriented to social needs

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[60] Selected operating and financial characteristics of nursing homes, United States: 1973-74. National Nursing Homes Survey Series 13, No. 22, DHEW Publication No. (HRA) 76-1773, U.S. Govt. Printing Office, Washington, D.C., December 1975.

than the first type, but there is little exclusivity in their goals, participants or services. They appeal to participants exhibiting a variety of characteristics, including mental problems and differences in health status rather than physical disabilities. (The study also reports that programs that are clearly targeted toward a specific post hospital, rehabilitation-needing client group serve participants who suffer many limitations in activities of daily living.) Those which serve multi-purpose goals admit clients who most often need fewer health care services, are less impaired, and often come to the day care program before going to a nursing home rather than after an institutional stay. Hence, two models of day care were identified; model one programs are predominantly rehabilitation oriented, while model two programs are multi-purpose, and usually less health oriented than model one programs. None of them entirely shuns a health care orientation. Likewise, some serve participants with psychiatric problems, others do not. They assume that model two programs have fewer professional staff, and their costs are lower--perhaps the reason for not catering to participants who need serious health care.[61]

Additional analysis of characteristics of the two models of adult day care studied by Weissert demonstrate a

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[61] Ibid.

great difference in the following areas which are of interest for this paper: (i) Admission criteria at model one requires that the participant "must need therapy", while model two does not have this explicit requirement but does accept persons with some physical or social dysfunction, (ii) Intake procedures at model one utilize "multidisciplinary" teams who use standardized forms and procedures while model two does this "informally." (iii) Referral sources for model one are "physicians" while the other model uses welfare departments, social service agencies, churches, mental health clinics, friends and relatives. (iv) Staffing--at model one, emphasis is placed on many registered, certified, or licensed health care professionals, on the other hand model two uses many unregistered, unlicensed, and uncertified personnel or referral to outside sources or both. (v) Services--model one has no home care except training of relatives in follow-up care while model two provides some offering in home health care or homemaker services, or both. (vi) Affiliation--inpatient health care facilities are a must in model one and model two uses community service agencies or freestanding. (vii) Funding for model one came from Medicaid and private health insurance, and model two receives funds from "formula grants", revenue sharing funds,

model cities funds, and demonstration grants. (viii) Cost per day--model one was $40.00 on average and model two $20.00. Finally, the percentage of participants with mental disorders at model one was 55 and model two 28.

CHAPTER III

DATA PRESENTATION AND DISCUSSION

This study incorporates properties of general system theory in analyzing relationships between relationships between independent and dependent variables. General Systems theory contends nothing can be studied as a lone entity and that general concepts can describe systems and the reaction between systems irrespective of the nature of the systems and their components. The systems model provides a useful overall conceptual framework within which otherwise--unconnected parts may be integrated.[62] The application of this approach enables the researcher to take a holistic view of the interactions of adult day care/rehabilitation participants with their environments and is a valuable method for considering outcomes and effectiveness in meeting community needs. Hall and Fagan conceive of a system as a set of parts or components together with relationships between the parts and between properties of the parts.[63] Thus a system becomes a group

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[62] Carole Lum O'Brien, Adult Day Care: A Practical Guide (California: Wadsworth Inc., 1982), p. 16.

[63] A. D. Hall and R. E. Fagan, "Definition of a System", in Modern Systems Research for the Behavioral Scientist, ed. W. Buckley (Chicago: Aldine Publishing Co.,1968),p.81.

of related structures, processes, or substances that together perform certain functions designed to achieve particular goals.

Sampling Frame Characteristics

According to Simon, no sampling frame can ever be a perfect representation of the population.[64] This study makes use of three different sampling frames in the State of Georgia focusing on (i) utilization of adult day care/rehabilitation centers as its primary unit of analysis. (there were only 35 centers registered with the Office of Aging , Department of Human Resources when the study was conducted), (ii) participation of those elderly patients suffering from Alzheimer's disease and related disorders, and (iii) adults aged sixty years and over enrolled at adult day care/rehabilitation centers (N=1201). These data are further broken down into categories of indicators: demographic, socio-economic, environmental, schedule of operation, affiliation, funding/reimbursement sources, utilization and client information, health status (percentage of degree of Alzheimer's disease and related disorders), special policy on admissions, special programs or services to the family, staff, cost and physical plant.

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64 Julian L. Simon, Basic Research Methods in Social Science (New York: Random House, 1969), p. 42.

These indicators are generally associated with the long-term needs of the elderly, and thus data are collected relative to these items. This information is also relative to the potential demand for adult day care/rehabilitation services. However, focus is on the idea that those adult day care and rehabilitation centers with existing special policy on admissions will be relatively inaccessible to some Alzheimer's disease and related disorders patients. In this sense, it can be further assumed that the adult day care and rehabilitation centers with a restrictive special policy on admissions will have less patients participating than adult day care/rehabilitation centers with relatively open policy on admissions.

A focus of this thesis is the concern with personal values that are created when human beings interact with bureaucratic aspects of their environment. Bureaucratic workplaces shape the values of workers according to Chackerian and Abcarian; "operational values" describes those values that are created in the workplace to satisfy bureaucratic ends but may be inconsistent with personal needs and development.[65] We address operational values

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65 "Work in America," Report of a Special Task Force to the Secretary of Health, Education and Welfare (Cambridge: MIT Press, 1969), p. 21.

here because they may ultimately be diffused to the family and policy, since they can be vehicles of bureaucratic power.

With respect to data collection, out of a total of 35 questionnaires sent, a total number respondents equalled 88.6 percent (N=31). It was recognized that the high rate of returns eliminated possibilities of biases. A sum of 19 counties out of Georgia's total number of 159 counties was covered. These included both rural and urban counties.

Key Variables: An important variable in this study is the schedule of operations. This set of questions inquired as to the number of days and hours of operation. In order to provide information on participation or non-participation of Alzheimer's disease and related disorder patients in these centers, questions sought data on the operations schedule.

The importance of including a schedule of operations is that the study seeks to identify whether or not the periods that the centers operate conflict with appropriate caregivers of patients of Alzheimer's diseases, or (which can cause impact on participation).

Affiliation with agencies and organizations by adult day/rehabilitation programs plays a significant part in terms of making policies and regulations for running these services. These affiliate organizations sometime carry the

responsibility of funding and reimbursement procedures. The instrument has a category of seven affiliation bodies, namely medical center/hospital, church/synagogue, city/state/federal government agency, nursing home, life care community, no affiliation and others. This category provides more detailed data on the breakdown of adult day care and rehabilitation programs and their respective affiliate organizations.

Funding and reimbursement sources are the critical subject when one is addressing issues that affect the elderly, especially those patients suffering from Alzheimer's disease. Many demographic forecasts predict increases in the total number of older persons and especially in the age cohort of 85+ individuals, since the elderly are the predominant consumers of long-term care services. Therefore, it can be assumed that there will be a dramatic increase in the demand and amount of private and public monies spent on long-term care services.

The American Journal of Public Health reports that aggravating the problem is the fact that health, social and personal care services in the community tend to be fragmented and often unresponsive or unavailable to Alzheimer's patients and their families. Hay and Ernst have demonstrated clearly the tremendous monetary costs of caring

for chronically demented patients with Alzheimer's disease.[66]

The instrument also focused on the percentage of funds or reimbursements received from the following sources: Older American Act, Medicaid, Client Fees, Social Services Block Grant, Private Endowment--gifts, donations, state appropriations, client fees, and others. The data demonstrate which funding or reimbursement sources provide more for both demented patients and elderly in these programs.

Data Concerning the Elderly Population (Utilization and Client Information)

Also included are demographic indicators recording the total number of persons age 60 and 85+ who participated at adult day care/rehabilitation centers during the month of October 1987.

Data on the number of clients at the 33 centers are broken down into three categories:

(i) participation per day and week

(ii) degree of Alzheimer's disease or a related disorder diagnosis ranging from zero to one hundred (0-100%) percent.

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[66] J. W. Hay and L. Ernst, "The Economic Cost of Alzheimer's Disease," American Journal of Public Health (1987): 77:9, pp. 1169-1175.

(iii) maximum number of slots or clients that can be served per day.

Data on special services the centers provide for clients with Alzheimer's disease or related dementia constituted a major focus of this study. Centers were requested to attach a copy of the Special Policy on Admissions (if applicable). Also requested were special programs or services to the family of the demented participant. The center was asked to describe these services.

Data relating to staffing patterns were also obtained. The needs of the adult day care/rehabilitation center participants are such that they require, at times, intensive management of their disabilities and at other times, psychosocial stimulation. The type of model of the program also is a determining factor regarding appropriate staffing patterns. Furthermore, the ratio of professional staff to participants in these programs depends on the needs of the population being served. The questionnaire focused on two areas of staffing patterns including:

(i) the usual direct care staff/client ratio and (ii) a listing of personnel employed by title or job category and whether they are full or part-time employees.

Questions on socioeconomic indicators attempting to obtain data on the cost of running the services, and client

charges at the center were included. The following were asked:

(i) if there was a sliding fee scale and what range

(ii) client charge or fee per day of day care

(iii) client cost per day care.

This analysis will illustrate if the services are run at profit or loss.

Data on environmental indicators include a description of the physical plants of the adult day care/rehabilitation centers. A number of factors relating to characteristics and functions of housing of day care/rehabilitation patrons are vital (e.g.) space per person, room for activities, location, etc. Information was obtained to answer questions about the

A. physical plant including four areas:

(i) number of rooms regularly used by the programs (excluding storage rooms and hallways)

(ii) available size of square feet per person (excluding halls, kitchens, storage rooms, bathrooms and offices)

(iii) if the plant had an enclosed outside area

(iv) characteristics of physical plant which believed to be particularly important for managing clients with Alzheimer's disease or related disorders.

Utility and Limitations of Study

From this analysis, findings can be presented to agencies and community groups that lobby for issues that affect the elderly--in particular the Alzheimer's disease and related disorders patients, who are a major focal point of concern in the United States and a critical issue to the citizens of Georgia. The results could enhance legislators' sensitivity to the issue and perhaps more specialized Alzheimer's adult day care and rehabilitation centers can be established so as to meet demand of this service.

The methodological limitations of the study include the following: (i) the study will include only thirty-three adult day care and rehabilitation centers out of 35 and nineteen counties out of 139 in Georgia. This is because of inaccessibility to some other facilities not registered with the Office of Aging; (b) the study will only cover those elderly persons with Alzheimer's disease and related disorders who participated at adult day care and rehabilitation centers, thus excluding those who could not attend the facilities due to various reasons.

Findings

Findings from the survey of 33 adult day care and rehabilitation centers and their utilization by patients suffering from Alzheimer´ disease and related disorders in Georgia are as follows:

Out of a total of 35 adult day care rehabilitation centers examined, 31 (88.6 percent) centers responded while 4 (11.4 percent) surveys were not returned. Among the 31 centers, three different types of centers were observed; these were thirteen (41.9 percent) adult day care centers; sixteen (51.6 percent) adult day rehabilitation centers; and two (6.5 percent) combination day care centers (see Table 2).

Table 2

Analysis of Types of Centers

Type	No.	Percentage
Adult Day Care	13	41.9
Adult Day Rehabilitation	16	51.6
Combination Day Care	2	6.5
Total	31	100

The adult day care/rehabilitation centers surveyed were all located in nineteen (13.7 percent) counties in the

state of Georgia. Three counties, Chatham, Dekalb and Fulton had the highest concentration of centers in the state with each having four (12.9 percent) centers. Dekalb County demonstrated the largest number of patients suffering from Alzheimer's disease and related disorders 116 (38.5 percent) of the total 301 patients, while six (31.6 percent) of the counties, (Bibb, Clarke, Dodge, Floyd, Muscogee and Richmond had absolutely no Alzheimer's patients. Chatham county illustrated the greatest number of participants without Alzheimer's dementia, 183 (25.8 percent) out of 708 participants. On the other hand, Clayton county had the least with no patients suffering from dementia. The majority of adult day care programs in one county, (30.8 percent) were found in Dekalb, followed by Chatham with three (23.1 percent). Furthermore, Dekalb County represented the adult day care center with the most patients of Alzheimer's disease, 76 (25.2 percent), and Chatham represented the county with the highest number of non-Alzheimer's disease and related disorders at both adult day care centers, 183 (18.1 percent) of the entire participants (see Table 3).

Table 3

Counties Surveyed by Selected Variables

Name of County	Frequency	ADC	ADR	Combin. Centers	Alzh. Patients	%	Non Alzh. Patients	%	Total Participants
Baldwin	1	-	1	-	6	2.0	6	0.8	12
Barrow	1	-	1	-	3	1.0	29	4.2	32
Bibb	1	-	1	-	0	0.0	32	4.5	32
Chatham	4	3	1	-	43	14.3	183	25.8	226
Clarke	1	-	1	-	0	0.0	37	5.2	37
Clayton	2	1	-	1	44	14.6	0	0.0	44
Cobb	1	1	-	-	23	7.6	29	5.0	52
Columbia	1	-	1	-	2	0.7	8	1.1	10
Dekalb	4	4	-	-	116	38.5	33	4.7	149
Dodge	1	-	1	-	0	0.0	15	2.1	15
Dougherty	1	-	1	-	13	4.3	28	4.0	41
Floyd	1	-	1	-	0	0.0	27	3.8	27
Fulton	4	1	3	-	23	7.6	18.1	18.2	151
Gwinnett	1	-	1	-	2	0.7	10	1.4	12
Hall	2	1	1	-	20	6.6	27	3.8	47
Muscogee	2	1	1	-	0	0.0	81	11.4	81
Richmond	1	1	-	-	0	0.0	18	2.5	18
Ware	1	-	1	-	5	1.7	12	1.7	17
Whitfield	1	-	-	1	1	0.3	5	0.7	6
Total	31	13	16	2	29.8	100	70.2	100	1009

The entire study covered a total of 1009 elderly participants. Among the 1009 individuals, 301 (29.8 percent) were categorized as patients with dementia. The remaining 708 (70.2 percent persons were considered to be Alzheimer's disease and related disorders free. Adult day care centers served 219 (72.8 percent) demented persons, adult day rehabilitation centers catered for 52 (5.2 percent) Alzheimer's patients while combination centers accommodated 30 (3 percent) patients. The Alzheimer's disease free participants at centers were as follows, adult day care centers 297 (42.0 percent), adult day rehabilitation centers, 406 (57.3 percent) and combination centers 5 (0.5 percent) (see Table 4).

The study further indicated that in a total number of 301 Alzheimer's patients 28 (9.3 percent) white males, 112 (37.2 percent) white females, 21 (7 percent) non-white males and 58 (19.3 percent) non-white females participated at adult day care centers; 6 (2 percent) white males, 11 (3.7 percent) white females, 4 (1.3 percent) non-white males and 31 (10.3 percent) non-white females participated at adult day care and rehabilitation centers; while 9 (3 percent) white males, 12 (4.00 percent) white females, 5 (1.7 percent) and 4 (1.3 percent) non-white females participated at combination centers. White females represented the

Table 4

Total Participants in the Study (N=1009)

Age Groups	Number of Participants							
	Male		Female		Male		Female	
	Total Census	ADRD* Only	Total Census	ADRD* Only	Total Census	ADRD* Only	Total Census	ADRD* Only
60	12	0	24	2	16	1	43	10
61-64	9	3	15	6	6	3	37	16
65-74	20	8	64	74	40	2	76	19
75-84	16	12	115	24	42	9	85	20
85+	25	20	21	29	30	15	12	28
Total	82	43	239	135	134	30	253	93

*See attached definitions.

Table 5

A Breakdown of Participants with and without Alzheimer's Disease in the Entire Study (N=1009)

Alzheimer's	Non-Alzheimer's
301 - 29.8%	708 - 70.2%

A Breakdown of Alzheimer's and Non-Alzheimer's Participants By Centers

	Alzheimer's		Non-Alzheimer's	
ADC	219	72.8%	297	41.9%
ADR	52	17.3%	406	57.3%
Combination	30	9.9%	5	0.8%
Total	301	100%	708	100%

largest number of Alzheimer's patients who were 135 (44.8 percent), followed by non-white females, 93 (30.9 percent), followed by white males 43 (14.3 percent) and lastly non-white males 30 (3 percent) (see Table 6).

Table 6

Alzheimer's Patients By Race, Gender and Centers

Center	Number of Patients	Race			
		White Male	White Female	Non-White Males	Non-White Females
ADC	219	28(9.3)	112(37.2)	21(7.0)	58(19.3)
ADR	52	6(2.0)	11(3.6)	4(1.3)	31(10.3)
Combination	30	9(3.0)	12(4.0)	5(1.7)	4(1.3)
Total	301	43(14.3)	135(44.8)	30(10.0)	93(30.9)

Alzheimer's Patients by Superlative Degree of Comparison

White Female = 135(44.8%)
Non-white Female = 93(30.9%)
White Males = 43(10.0%)
Non-white Males = 30

Evaluation of Adult Day Care and Rehabilitation Center with "Special Policy on Admission"

Of the 31 programs studied, 11 (35.5 percent) utilized "special policy on admission" as a criteria for participation of prospective elderly at at adult day care and rehabilitation centers. These included a variety of 8 (25.8 percent) ADC; 2 (6.5 percent) ADR and 1 (3.2 percent) combination centers. In contrast, 20 (64.5 percent) did not use "Special Policy on Admission" as a criteria for eligibility at their programs. The breakdown of centers included 5 (16.1 percent) ADC, 14 (454.2 percent) ADR and 1 (3.2 percent) combination centers (see Table 7).

Table 7

ADC/R Centers Reporting Existence of "Special Policy on Admission"

	Policy in Existence	Policy Absence
ADC	8 (25.8)	5 (16.1)
ADR	2 (6.5)	14 (45.2)
Combination	1 (3.2)	1 (3.2)
Total	11 (35.5)	20 (64.5)

Of the total 13 ADCs in the study, 8 (61.5 percent) had a "special policy on admission"; while ADR programs

totalling 16 had only 2 (12.5 percent) centers with "special policy on admission" and cut of a total of 2 combinations, 1 (50 percent) had policy for admission.

Data indicate that a total of 516 elderly persons were enrolled at 13 adult day care centers during the period of the study. Of these 516 persons, 219 (42.4 percent) suffered from Alzheimer´s disease, within these 219 patients 124 (56.6 percent) enrolled at 7 adult day care centers with "special policy on admission", while 95 (43.4 percent) enrolled at 3 adult day care centers without "special policy on admission"; the remaining 297 (57.6 percent) did not suffer from Alzheimer´s disease, and 110 (37 percent enrolled at 6 adult day care centers without "special policy on admission", whereas 187 (63 percent) enrolled at 5 adult day care centers suffered no Alzheimer´s disease. One adult day care center with special policy on admission, (specializing on ADRD patients) had no patient of Alzheimer´s; 2 adult day care centers without "special policy on admission" showed no Alzheimer´s patients; at the same time, 2 adult day care centers with "special policy on admission", (specializing on ADRD patients) had none of Alzheimer´s free participants. Further observation signified 3 ADRD adult day care centers with restrictive special policy on admission, also accepting the greatest

severity degree of Alzheimer's diagnosis (75-100 percent), a total of 2 adult day care centers accepting the next greatest severity degree of ADRD patients (50-75 percent), 1 with special policy and the other without, 3 adult day care centers accepting the moderate severity of ADRD patients (25-50 percent). Among these three, two utilized special policy, while one had none, of the remaining 5 adult day care centers catered for the lowest severity of ADRD patients, 2 adult day care centers with special policy and 3 without special policy. Special programs or services to the family of adult day care participants, were available at 8 adult day care centers; 7 centers were in the category of restrictive special policy on admissions and 1 had no restrictive policy, and 5 centers provided no special programs or services to the family of these (1 center required special policy and 4 required none). Dekalb County represented the most frequency of adult day care centers forcing "special policy on admission" 40 (18.2 percent) (3), ensued by Chatham 31 (14.2 percent) (2), Cobb 23 (10.5 percent) (1), Clayton 15 (6.8 percent (1), and Hall County 15 (6.8 percent (1). Concurrently in the category of adult day care centers without existing special policy on admission, Dekalb County demonstrated the highest utilization by Alzheimer's patients--76 (34.7 percent),

followed by Chatham County, 12 (5.5 percent), Cobb County 7 (3.2 percent) and 2 had no Alzheimer's patients at all (see Tables 8 and 9).

Table 8

Adult Day Care Centers with Existing "Special Policy on Admission"

County	Alzheimer Patients	Non-Alzheimer Participants	Special Programs to the Family of Participants	Alzheimer Diagnosis Severity
Dekalb	22(10.0)	0(0)	Yes	4*
Dekalb	14(6.4)	13(4.4)	Yes	3
Dekalb	4(1.8)	8(2.7)	No	1
Chatham	31(14.2)	23(7.7)	Yes	2
Chatham	0(0)	27(9.0)	Yes	4*
Cobb	23(10.5)	29(9.8)	Yes	2
Clayton	15(6.8)	0(0)	Yes	4
Hall	15(6.8)	10(3.4)	Yes	1
	124	110		

*Adult day care centers (ADCs) for Alzheimer's Disease and Related Disorder (ADRD). Alzheimer's diagnosis severity 1 = 0-25%; 2 = 25-50%; 3 = 50-75%; 4 = 75-100%.

Table 9

Adult Day Care Centers without Existing "Special Policy on Admission"

County	Alzheimer Patients	Non-Alzheimer Participants	Special Programs to the Family of Participants	Alzheimer Diagnosis Severity
Dekalb	76(34.7)	12(4.0)	No	3
Chatham	12(5.5)	56(18.9)	No	1
Fulton	7(3.2)	39(13.1)	No	1
Muscogee	0(0)	62(20.9)	No	1
Richmond	0(0)	18(6.0)	Yes	2
	95	187		

Alzheimer's diagnosis severity 1 = 0- 5%; 2 = 25-50%; 3 = 50-75%; 4 = 75-100%.

Data show that a total of 458 elderly persons were enrolled at 16 adult day rehabilitation centers at the time of the study. Of these 458 persons, 52 (11.4 percent) suffered from Alzheimer's disease, and within these 52 patients, 18 (34.6 percent) enrolled at 2 adult day rehabilitation centers with existing "special policy on admission" while 34 (65.4 percent) enrolled at 14 adult day

rehabilitation centers without existing "special policy on admission"; the remaining 406 (88.6 percent) did not suffer from Alzheimer's disease; of these 406 participants, 46 (10.0 percent) enrolled at 2 adult day rehabilitation centers with existing "special policy on admission" and 360 enrolled at 14 adult day rehabilitation centers without existing "special policy on admission," of these 14 adult day rehabilitation centers, 7 of them had no Alzheimer's patients altogether, 11 adult day rehabilitation centers offered no "special programs/services to the families of participants, 3 centers provided such service. In the category of adult day rehabilitation centers with "special policy on admission" one program offered special program/services to the families of participants while the other did not, and both of these programs accepted participants with 25-50 percent degrees of Alzheimer's diagnosis. On the other hand, the adult day rehabilitation programs without "special policy on admission" reflect 13 out of 14 centers to have no special program/services to the families of participants, only one adult day rehabilitation center offered the service (see Tables 10 and 11).

Table 10

Adult Day Rehabilitation Centers with Existing "Special Policy on Admission"

County	Alzheimer Patients	Non-Alzheimer Participants	Special Programs to the Family of Participants	Alzheimer Diagnosis Severity
Baldwin	6(11.5)	6(11.5)	No	2
Fulton	12(23.1)	40(76.9)	Yes	2
Total	18	46		

Table 11

ADRs without Existing "Special Policy on Admission"

County	Alzheimer Patients	Non-Alzheimer Participants	Special Programs to the Family of Participants	Alzheimer Diagnosis Severity
Barrow	3(5.8)	29(7.1)	No	1
Bibb	0(0)	32(7.9)	No	1
Chatham	0(0)	77(18.9)	No	1
Clarke	0(0)	37(9.1)	No	1
Columbia	2(3.8)	8(1.9)	No	1
Dodge	0(0)	15(3.7)	No	1
Dougherty	13(25)	28(6.9)	Yes	2
Floyd	0(0)	27(6.7)	No	1
Fulton	0(0)	25(6.2)	No	1
Fulton	4(7.7)	24(5.9)	Yes	1
Gwinnett	2(3.8)	10(2.5)	No	1
Hall	5(9.6)	17(4.2)	No	1
Muscogee	0(0)	19(4.7)	No	1
Ware	5(9.6)	12(2.9)	Yes	1
Total	34	360		

The final data indicate that there was a total of 2 combination centers which involved 35 total participants. Of these 30 (86.7) persons suffered Alzheimer's disease and 5 (14.3 percent) did not suffer from Alzheimer's. One

combination center, with existing "special policy on admission", there was only one (2.9 percent) Alzheimer's patient and the other without "special policy on admission" there were 29 (82.9 percent); the combination programs indicate absence of "special programs/services to families of participants, and 0-25 percent Alzheimer's diagnosis severity at both centers (see Tables 12 and 13).

Table 12

Combination Adult Day Care Centers with Existing "Special Policy on Admission"

County	Alzheimer Patients	Non-Alzheimer Participants	Special Programs to the Family of Participants	Alzheimer Diagnosis Severity
Whitfield	1	5	No	1

Table 13

Combination Adult Day Care Centers without Existing "Special Policy on Admission"

County	Alzheimer Patients	Non-Alzheimer Participants	Special Programs to the Family of Participants	Alzheimer Diagnosis Severity
Clayton	29	0	No	1

Staffing at Adult Day Care/Rehabilitation Centers

Of the 31 programs, 20 (64.5 percent) show registered Nurses (RNs) employed either as directors of present at the centers. Adult day rehabilitation centers had most registered nurses as directors of the centers, 10 (32.3 percent), followed by adult day care centers 8 (25.8) percent) and combination, 2 (6.5 percent). The next dominant career was Master's of Social work or Social Work, these were present at 19 (61.3 percent) centers, followed by LPNs, 12 (38.7 percent). There were 16 (51.6 percent) directors/managers or supervisor employee full time at 31 centers. The range of staff to client ratio ranged between 1:1-1:15, with 1:3 as the most frequency (see Table 14).

Cost

The client charge/fee per day of day care, and the client cost per day indicate a wide variety of fees, since funding of services also comes from a wide variety of sources. The mean charge was approximately $35.00 for most, and cost was in many cases more than the charge. Out of 31 centers, only 10 (32.3 percent) programs had sliding fees, the rest, 21 (67.7 percent) did not respond to the question.

Table 14

Staffing
(Paid, Volunteer, Student, Consultant)

	Centers Reporting	Center Director	Centers Reporting Paid Staff Person	Centers Reporting Full-time Staff	Centers Reporting Part-time Staff Person	Volunteers
Nurse (RN)	31	13	10	19		
Nurse (LPN)			6	4	2	
Master Social Worker		3	16	11	10	
Program Coordinator	31	1	1	3		
Director/Manager Supervisor	31	16	2	12	3	
Drivers Aides			15	10	5	
Miscellaneous Aides				12	11	
Volunteers						2
Health Educator				6	4	
Activity Director				14	8	
Secretary					9	
Rehabilitation Coordinator				7	2	
Social Service Coordinator				5	2	
Therapeutic Recreation Specialist				2	1	
Cook				10	9	
Arts/Crafts, Creativity Person				5	8	
Custodian					1	
Housekeepers				6	4	

20 Cnts = RN on program 64.5%; 41.9% RN Div.
19 Cnts = SW 61.3%; 9.7% SW Div.
12 Cnts = LPN 38.7%; 51.6% Div. Mgr. Sup.
51.
ADC = RN = 8
ADR = RN = 10
Comb = 2

Physical Plant

The study focuses on characteristics of physical plant which the respondent believed were particularly important for managing clients with Alzheimer's disease or a related disorder. Of the 31 centers, 10- (32.3 percent) adult day care centers, and 7 (22.6 percent) adult day rehabilitation centers reported suitable physical plant for Alzheimer's patients, while 8 (25.8 percent) adult day care, 8 (25.8 percent) adult day rehabilitation centers and 2 (6.5 percent) are reported not suitable physical plant for servicing Alzheimer's patients.

Schedule of Operation

Of the 31 centers studied, 12 (38.7 percent) adult day care, 13 (41.9 percent) adult day rehabilitation and 2 (6.5 percent) combination centers operated for five days; 2 (6.5 percent) adult day rehabilitation centers operated for four days, 1 (3.2 percent) served for three days and 1 (3.2 percent) adult day care center opened for seven days. In terms of hours of operation, the majority of programs opened their services for 8 hours, in exception of one center which reported 24 lows.

Affiliation

Respondents reported 4 (12.9 percent) adult day care, 7 (22.6 percent) adult day rehabilitation and 1 (3.2

percent) combination centers affiliated under the category of "other"; 3 (29.0 percent) adult day care and 8 (16.1 percent) adult day rehabilitation centers had no affiliation; 3 (3.0 percent) adult day care centers and 1 (3.2 percent adult day rehabilitation had "more than one affiliation", 3 (29.0 percent) adult day care, 1 (3.2 percent) adult day rehabilitation and 1 (3.2 percent) combination were affiliated to either "city, state or federal government agencies" and 1 (3.2 percent) adult day rehabilitation centers affiliated to a medical center or hospital.

Funding and Reimbursement Sources

Thirteen (41.9 percent) adult day care, 9 (29.0 percent) adult day rehabilitation, and 2 (6.5 percent) combination centers had more than one source of funding and reimbursement. Five (16.1 percent) adult day rehabilitation centers received their funding or reimbursement through "Medicaid", one (3.2 percent) adult day rehabilitation centers through Older Americans Act and one (3.2 percent) adult day rehabilitation centers had no funding or reimbursement benefits.

CHAPTER IV

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This study examined participation of patients suffering from Alzheimer's disease and related disorders at 31 adult day care/rehabilitation centers registered with the Department of Human Resources (DHR), Office of Aging in Atlanta, Georgia. Major attention was focused on those adult day care/rehabilitation centers with existing "special policy on admission." It was hypothesized that those centers, because of an existing "special policy on admission" would be relatively inaccessible to some patients of Alzheimer's disease and related disorders; on the other hand, those without an existing "special policy on admissions" would be relatively accessible to Alzheimer's patients. Following this hypothesis, it was assumed therefore, that adult day care/rehabilitation centers with a restrictive "special policy on admission" will have less patients participating than the adult day care/ rehabilitation centers with relatively open policy on admissions. The study was to further determine the following: (i) the extent to which bureaucracy plays a role in the current social services rendered by these centers in meeting the needs of Alzheimer's disease and related disorders patients, and (ii) the extent to which the

existence of special policy on admission promotes (a) stratification, (b) centralization, and (c) rationalization at facilities where the policy is enforced. Demographic variables such as race, age and sex would be observed.

The hypothesis that those ADC/R centers with an existing special policy on admission will be inaccessible to some Alzheimer's patients is confirmed. With respect to patient distribution, there were 124 Alzheimer's patients at ADC, 18 patients at ADR and 1 patient at combination centers (N=143) with existing special policy on admission; while there was a total of 158, (ADC 95, ADR 34 and Combination 29) at programs without existing "special policy on admissions". Indeed, it can be deduced that, because of more Alzheimer's patients at ADC/R centers with a relative open policy on admissions, accessibility to services was greater. The smaller total number of Alzheimer's patients at centers with restrictive special policy on admissions does confirm the hypothesis that centers of this calibre are inaccessible, hence the decrease of Alzheimer's participants. Another remarkable observation exists in one adult day care center specially serving Alzheimer's disease and related disorders patients; there were no participants in this category. In the three ADRD day care centers, with an existing special policy on admissions, there was only a total of 45 (14.9) patients.

Findings reveal that there were more black (387) than white (321) participants; however, the white females (135) suffering from Alzheimer's outnumbered their black counterparts (93, also the total number of patients in the entire study). The age bracket 65-74 years old, indicates the highest number of white females suffering from Alzheimer's and the lowest being 60 years old age bracket with 1 non-white male. Further indication is the greater number of Alzheimer's patients enrolled at ADC (219) in contrast to ADR (52), whereas traditionally, it would be expected to have more patients at the latter since it is a medical model day care program primarily geared to serve the mentally ill or seriously disabled population who suffer from chronic health problems. The medical model program is also recommended to serve psychiatric patients especially those who are in need of long-term health maintenance similar to Alzheimer's disease patients. The fact that ADR centers (16) outnumbered ADC (13) centers makes this assumption feasible. In addition, a total of 14 ADR centers in the study had no existing special policy on admission thus greater participation of Alzheimer's disease and related disorders patients was expected than observed.

An implication can be made that to some degree bureaucracy does play a role and impact social services

rendered by ADC/R centers attempting to meet needs of Alzheimer's patients. This phenomenon is supported by the fact that publicity for a majority of centers as done through telephone calls, brochures, flyers posted on bulletin boards, newspaper articles, invitations sent to community-health services and organizations. In this way, caregivers with a minimal level of education and patients from relatively poor backgrounds tend to be left out of the scene. In this sense, seemingly, a small segment of populations will benefit from the services. One of the criteria in a special policy on admission, requires that a prospective participant not be in need of "24-hour" attention. This policy readily hinders Alzheimer's patients because they need constant "24-hour" attention. An individual must be able to assimilate into a group setting- an unbecoming expectation from a demented patient whose mind wanders all the time. Some centers require that participants be referred by the Community Care Social Program Case Managers or other community resources; all clients must be continence of bowel and bladder; able to feed self, alert enough to try to help with transfer when needed; in need of medical monitoring and non-hostile clients will be accepted. Other centers will only serve those persons certified under Social Services Block Grant

(SSBG) (Title XX) (of the Social Security Act and for reimbursement for social services), and Title III guidelines of the Older Americans Act. Medical history and consent from the doctor must be obtained from the person's doctor before enrollment and eligibility emphasis are on persons who live alone. In conclusion, it can be clearly recognized that the criteria for admission to the centers program are determined by the program's model type. Since admission criteria are part of the center's program publicity, the community residents have information regarding the kind of people the program aims to serve.

In regard to promotion of centralization, an examination of all the data indicates that a variety of ADC/R centers were funded by various sources. These funding sources range from medical/hospital centers, foundations, city/state/federal/government agencies, etc, and the source of funding determines the policies, participation of clients, and in general makes regulations toward the facility it is funding. For example, corporate foundations are said to be extensions of profit-making corporations and as such, are interested in funding local impact programs that will help the parent corporation's images in the community. Similarly, special purpose foundations provide funding for programs benefitting and reflecting their

special interests. The limitations imposed by government regulations have tended to distort the emphasis in ADC/R so that frequently the funding available determines what needs will be met. It is reported that in those states in which Title XX funds are allocated, the programs are primarily health-focused. A distortion is said to exist in the effect that these limits have on middle-income elderly. Medicaid coverage is for indigent citizens. Medicare, for which many of them do qualify, does not yet extend sufficiently to adult day care. All of the other programs give preference to the low-income elderly. Middle-income elderly are as vulnerable to the diseases of old age as are low-income elderly and are unable to support their own care for very long.

Finally, promotion of rationalization as a third factor of bureaucracy, is heightened by the implementation of restrictive policy on admission centers around budget constraints, lack of skilled human resources to manage the facilities, and the dilemma or concern surrounding the uncertainty of full recovery of Alzheimer's disease and related disorders patients in becoming functional members of the community again, "which is the ultimate goal of the adult day/care/rehabilitation centers". When a program considers its staffing pattern, emphasis is placed on a

close match between staff capabilities and needs of the participants. The other crucial concern is the ratio of professional staff to participants and its dependability on the needs of the population being served. It is thought that without a team effort in planning, implementing and evaluating the participants' care plans, fragmentation will occur. On the other hand, the overemphasized selection of staff can impede participation of more clients at centers.[67]

Study Recommendations

The results of the study demonstrate a need for specialized adult day care or rehabilitation programs for those patients suffering from Alzheimer's disease and related disorders.

During the terminal stage of Alzheimer's or a similar disorder, when chronic unpredictable incontinence presents a problem and when communication has become minimal, most patients require 24-hour care outside the home (Ryan-Dukes, 1981)[68]. Also, the lack of insight which seems to characterize persons with cognitive impairment presents special

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[67] P. Ryan-Dukes, Caring for the dementia patient, Veterans Administration Medical Center, Seattle, WA, 1981).

[68] B. Cox Reitler & R. Hanley, Problems of mentally ill elderly as perceived by patients, families, and clinicians. The Gerontologist, 1981, 21:165-170.

difficulties for both the patient and the caregiver Reitler et al., found that cognitive impaired persons living in the home saw themselves as suffering no significant problems in activities of daily living, in personal health, or in family relationships; professional persons and family caregivers saw the same people as having problems in almost every area of life. For the person impaired, this can lead to the feeling of being interfered with and manipulated; for the person giving care, to feelings of being obstructed and unappreciated.

The study also indicates the objectives of adult day care/rehabilitation services which stress that their participants need to be those not needing 24-hour attention, and/or one to one staff client ratio. Therefore, this requirement totally excludes those Alzheimer´s patients. The employed staff analysis indicated no presence of a trained gerontologist and this suggests a need of expertise in this area. There is also a need to involve caregivers and participants in the development of the dementia care programs in the provision or arrangement for dementia specific training for caregivers, and as volunteers and workers providing respite care in the day centers. Past studies, and projections, as well as this research, indicate a growth of dementia patients. It is therefore

imperative that appropriate preparations (primarily, the development of more day care centers for these persons) be undertaken. One of the vital factors to be addressed also is the environmental design requirements for Alzheimer's disease patients. This study has shown quite a number of programs which were unable to provide for these patients due to their physical plants, which were considered not suitable for wandering people. Designers, planners and caregivers should consider the practical problems of furniture selections, spatial arrangement, lighting, textures, patterns, color and architectural features. Interior planning which takes into consideration these variables can promote the health, welfare and safety of users. Vision limitations such as farsightedness, decreased ability to adapt to changes in lighting conditions and an increased sensitivity to glare are reported not uncommon in the Alzheimer's disease patient. The Alzheimer's disease patient is said to have a tendency to experience social withdrawal as the disease progresses. Therefore, to encourage social interaction, interior components should be selected and arranged to assist the individual in ease of movement from one area to another. It must be recognized that although human beings have a great propensity to adapt to less than ideal conditions, the aged, particularly those

with Alzheimer's disease may have more difficulty. It is concluded that the development of more adult day care centers for Alzheimer's disease and related disorders patients, with more emphasis directed to their specific needs, must become a greater reality if this significant part of our population is to receive the care to which they are entitled.

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